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**Impact of Covid-19 on clinical care and lived experience of systemic sclerosis: An international survey from EURORDIS-Rare Diseases Europe**

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Keywords:	Systemic sclerosis, Scleroderma, Covid-19, Clinical-care, Emotional well-being, Telemedicine
Abstract:	<p>Introduction: Outcomes related to Covid-19 in systemic sclerosis (SSc) patients could be influenced by internal organ involvement and/or immunosuppressive treatment, leading to efforts to shield patients from Covid-19 transmission. We examined the impact of Covid-19 on the lived experience of SSc with regards to other aspects of daily living including occupation and emotional well-being.</p> <p>Method: Individuals with SSc or relatives/carers participated in an online survey, disseminated through international patient associations and social media pages, designed to examine the impact of Covid-19 on living with a rare disease.</p> <p>Results: Responses from 121 individuals (98% patients) from 14 countries were evaluable. Covid-19 was considered a probable/definite personal threat (93%) or threat for the individual they care for (100%). Approximately two-thirds of responders reported either cancellation or postponement/delay to appointments, diagnostic tests, medical therapies at home (e.g. infusions), surgery or transplant, psychiatry follow-up, or rehabilitation services. Twenty-six per cent reported at least one SSc medicine/treatment had been unavailable, and 6% had to either stop taking usual medications or use an alternative. Most reported online consultations/telemedicine via phone (88%) and online (96%) as being 'fairly' or 'very' useful. Respondents reported tensions amongst family members (45%) and difficulty overcoming problems (48%). Restrictions on movement left around two-thirds feeling isolated (61%), unhappy and/or depressed (64%), although the majority (85%) reported a strengthening of the family unit.</p> <p>Conclusions: Covid-19 has resulted in significant impact on the clinical-care and emotional well-being of SSc patients. Changes to clinical care delivery have been well-received by patients including telemedicine</p>

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# Impact of Covid-19 on clinical care and lived experience of systemic sclerosis: An international survey from EURORDIS-Rare Diseases Europe

## Original article

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2 Figures

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**Introduction:** Outcomes related to Covid-19 in systemic sclerosis (SSc) patients could be influenced by internal organ involvement and/or immunosuppressive treatment, leading to efforts to shield patients from Covid-19 transmission. We examined the impact of Covid-19 on the lived experience of SSc with regards to other aspects of daily living including occupation and emotional well-being.

**Method:** Individuals with SSc or relatives/carers participated in an online survey, disseminated through international patient associations and social media pages, designed to examine the impact of Covid-19 on living with a rare disease.

**Results:** Responses from 121 individuals (98% were patients with SSc) from 14 countries were evaluable. Covid-19 was considered a probable/definite personal threat (93%) or threat for the individual they care for (100%). Approximately two-thirds of responders reported either cancellation or postponement/delay to appointments, diagnostic tests, medical therapies at home (e.g. infusions), surgery or transplant, psychiatry follow-up, or rehabilitation services. Twenty-six per cent reported at least one SSc medicine/treatment had been unavailable, and 6% had to either stop taking usual medications or use an alternative. Most reported online consultations/telemedicine via phone (88%) and online (96%) as being ‘fairly’ or ‘very’ useful. Respondents reported tensions amongst family members (45%) and difficulty overcoming problems (48%). Restrictions on movement left around two-thirds feeling isolated (61%), unhappy and/or depressed (64%), although the majority (85%) reported a strengthening of the family unit.

**Conclusions:** Covid-19 has resulted in significant impact on the clinical-care and emotional well-being of SSc patients. Changes to clinical care delivery have been well-received by patients including telemedicine consultations.

**Key words:** Systemic sclerosis; Scleroderma; Covid-19; Clinical-care; Emotional well-being; Telemedicine.

## Introduction

Systemic sclerosis (SSc) carries a significant burden of disease-associated morbidity including reduced quality of life and high-associated mortality (1–4)[1–3]. Therefore, patients require regular clinical follow-up including screening for cardiorespiratory complications which can significantly improve survival (e.g. through the early detection of pulmonary hypertension) [4,5,65]. SSc is associated with significant emotional and social consequences including (but not limited to) anxiety, depression, fatigue, sleep disorders, body image dissatisfaction and sexual dysfunction. Patients experience fear and uncertainty about the future and make many adaptations to self-manage their condition. For example, patients describe the need for constant vigilance and cold avoidance to prevent attacks of Raynaud’s phenomenon and/or the development of new digital ulcers [6,77,8]. Patients with SSc also potentially require hospitalisation (both electively and urgently) throughout the course of their disease, including for the administration of intravenous-based vascular and immunosuppressive therapies. Furthermore, there still remains significant debate about the optimal timing for the safe reintroduction of immunosuppressive therapies in the context of confirmed Covid-19 infection [9].

Patients with SSc are potentially extremely vulnerable to poor outcomes including high mortality from Covid-19 (SARS-Cov-2) as a consequence of underlying major internal organ involvement and/or immunosuppressive treatment. A particular concern is the high prevalence of interstitial lung disease in SSc and potential lung injury related to Covid-19 infection [8,910,11]. There are also significant diagnostic challenges because Covid-19 pneumonia can share many similar radiological abnormalities with SSc-interstitial lung disease (e.g. ground glass opacities) [8,910,11]. In addition to the direct threats relating to Covid-19, patients with SSc have also faced disruption to their previous standards of care relating to ‘in person’ clinic appointments, therapeutic drug infusions, commencement of new immunomodulatory therapy and hospital-based investigations such as cardiopulmonary screening and cross-sectional imaging. However, international adjustments to the delivery of clinical care and new ways of working are likely to improve future care in SSc [12].

Against this background, our aims were to examine the impact of the Covid-19 pandemic on patients' with SSc 1) clinical-care and 2) other aspects of daily life including occupation and emotional well-being, and to identify where patients can be better supported.

**Method**

**Study design**

An international survey was designed by EURORDIS-Rare Diseases Europe, a non-profit and non-governmental alliance of over 900 patient organisations to understand how patients with rare disease experience the Covid-19 pandemic. The link to the survey was widely distributed including via the EURORDIS website [139], patient organisations and on social media pages. The survey was translated into 23 languages in order to ensure broad geographical patient representation. The survey took place between April and May 2020; either the patient themselves or a patient representative (relative/carer) could complete the survey. The survey (see **supplementary data**) was comprised of 30 questions which included patients' demographic information, current measures in place against the Covid-19 pandemic and the perceived threat, interruption and the perceived impacts in usual aspects of their clinical-care, changes to their occupation, and their emotional well-being. All responses were fully anonymised and there was no opportunity to verify diagnoses or responses. Respondents provided implied consent through completion of the voluntary survey. In view of the nature and distribution of the survey, the work was exempt from UK National Research Ethics Service and Health Research Authority regulations.

**Results**

**Responders' demographics**

A total of 121 patients-individuals, the majority of which were patients with SSc<sub>s</sub> responded to the survey from 14 countries worldwide. Most (>80%) individuals ('responders') reported living in Europe, with the majority in Italy (26%), Denmark (25%), Spain (18%), France (9%) or England (6%). When reported (n=118), the survey was completed by patients themselves (98%) or by their spouse or a patient representative (2%). The majority of responders were female (93%). Most (95%) responders were older than 35 years; in particular, either between 35-49 years (37%) or 50-64 years (45%). Less than one fifth of responders were either 65 years

or older (13%) or between 25-34 years (5%). Almost all (99%) responders identified that social distancing was in place including avoiding mass gatherings and maintaining distances from others when possible.

### ***Perceived impact and threat of Covid-19***

Over half of respondents indicated that the interruptions related to the Covid-19 pandemic were either 'probably' or 'definitively' affecting patients' health (59%) or well-being (69%). The majority of respondents (n=121) felt that Covid-19 posed either a 'high' (54%) or 'very high' (39%) personal threat. Around three-quarters felt that they had access to all the information they needed either 'some' (28%) or 'most' (44%) of the time.

### ***Impact of Covid-19 on clinical-care***

Two-thirds of patients (63%) were receiving at least part of their clinical care for SSc through a hospital. Of these, half (52%) did not attend the hospital themselves because they were fearful of contracting Covid-19. Respondents also indicated that they had been told not to attend the hospital if they became unwell for reasons other than Covid-19 (41%) or that the hospital/unit which provides care for SSc was closed (21%).

Figure 1 depicts the reported interruption in different aspects of care for patients with SSc provided by healthcare professionals since the beginning of the Covid-19 pandemic. Around two-thirds of responders reported either complete cancellation or postponement/delay to appointments with clinicians who manage their SSc, diagnostic tests (including blood tests, medical imaging and cardiorespiratory investigations), medical therapies at home (e.g. infusions), surgery or transplant, psychiatry follow-up, or rehabilitation services. One quarter (26%) of responders identified that at least one of their medicines/treatments needed for SSc had been unavailable temporarily when they visited their pharmacy or hospital, and 6% had to either stop taking it or take an alternative. Of those currently unaffected by disruptions to their medicines or treatment (n=82), the majority were either afraid 'a little' (55%) or 'a lot' (13%) about future possible problems if the pandemic continues.

### ***Experience of changes to clinical-care***



The majority of responders (where applicable) indicated that their experience to changes in clinical-care was either ‘fairly’ or ‘very’ useful with prescription by email (94%), online consultations or other forms of telemedicine including via telephone (88%), and online education and training to help them manage their SSc (96%).

**Impact of Covid-19 on occupation and emotional well-being**

***Impact on occupation***

The majority (90%) of respondents (where applicable, n=41) indicated that they had made changes to their working situation since the Covid-19 pandemic. Almost two-thirds were working from home (59%), 17% had to stop working and 15% significantly reduced their number of working hours.

***Impact on emotional well-being***

Figure 2 depicts the reported impact on patients with SSc emotional well-being since the Covid-19 pandemic. Respondents indicated that they felt tensions between their family members (45%), ‘sometimes’, ‘often’ or ‘very often’, they felt that they could not overcome their problems (48%), and two-thirds felt isolated (61%) or unhappy and/or depressed (64%). However, over three-quarters (85%) felt a strengthening of the family unit resulting from the Covid-19 pandemic.

**Conclusions**

The key findings from our study are that the Covid-19 pandemic has significantly impacted usual clinical-care, occupation and emotional well-being of patients with SSc. Patients experienced interruptions in all aspects of their clinical care including consultations, access to investigations including cardiorespiratory imaging, and access to drug therapies. Patients and their caregivers feel that these interruptions are likely to have a significant detrimental impact on the health of patients with SSc. The Covid-19 pandemic is having a major impact on the working life and emotional well-being of patients with SSc. However, in response there is evidence that the family unit is strengthening in order to face this unique challenge. Adding to an already unpredictable disease, the Covid-19 pandemic has been associated with significant fear and uncertainty about the future for patients with SSc and their caregivers.

Clinicians are faced with the challenge of maintaining a crucial continuity of care for patients with SSc, including psychological support and medicines management.

Patients with SSc require close clinical review and timely access to potentially tissue saving therapies. As the Covid-19 pandemic continues, clinicians are rapidly adopting existing and new technologies to provide clinical care including consultations and renewal of prescribed therapies. The vast majority (~90%) of responders felt that such alternative methods were either 'fairly' or 'very' useful. Ciurea and colleagues [141] recently reported their experience from the Swiss Clinical Quality Management cohort of the impact of the Covid-19 pandemic on the disease activity of patients with inflammatory rheumatological conditions (axial spondyloarthritis, rheumatoid arthritis and psoriatic arthritis). Despite a reduction in the number of consultations by half (52%) the number of remote assessments more than doubled. Reassuringly, the proportion of patients with disease flares remained stable and there was no detrimental impact on disease activity as assessed by patient-reported outcome measures. Accurate identification of patients with SSc and major internal organ-based complications (e.g. pulmonary hypertension and/or interstitial lung disease) [152] is required, with appropriate advice to shield

Patients with SSc and their caregivers require high-quality accessible information of appropriate readability throughout the course of their disease and are increasingly using internet/online sources of information and support (including patient-led organisations) to inform shared decision making [13,1416,17]. However, of concern, the overall quality and readability of internet-based SSc (and Raynaud's phenomenon) information (prior to the Covid-19 pandemic) has been reported to be poor [185]. In response to the Covid-19 pandemic, the World Scleroderma Foundation (WSF) has developed preliminary practical advice based for patient management which were developed virtually by experts in rheumatology and associated specialities [108]. This includes the need to limit visits to the hospital/clinic and that this must be balanced against the risk of disease flare on the individual level [108]. Also, telemedicine consultations have been strongly endorsed [108]. Furthermore, it has been acknowledged that temporary drug interruption of immunosuppressive treatment may be considered in Covid-19 infection, again highlighting the need to balance the risk of disease flare, and also the need for future research in this area

[108]. At the present time, no change in vascular/vasoactive therapy has been proposed for vascular and renal involvement in patients with SSc at risk of developing or experiencing Covid-19 [108].

As expected, in the earlier stages of the rapidly developing Covid-19 pandemic there were significant interruptions to existing treatment for patients with SSc. For example, Crisafulli et al [196], reported their single-centre (Brescia, Italy) early experience (since 23<sup>rd</sup> January) of an adapted, centralised outpatients for patients with rheumatic diseases. Of 64 patients with SSc who were receiving periodic intravenous iloprost infusions, the majority (73%) briefly discontinued their iloprost therapy. Despite interruption in treatment, there was no significant increase in new digital ulcers, but a slight increase in ulcer severity. A key aspect is that throughout this period there was regular communication with patients with SSc to optimise the timely reintroduction of treatment. There are also potential opportunities to learn from innovative models of care that have been developed in response to the Covid-19 pandemic in other chronic health conditions (e.g., diabetes mellitus) (20).

The EURORDIS survey has a number of important points for consideration. Although the sample size was fairly small (n=121) it has benefited from widespread geographical participation from patients with SSc, including translation of the survey into 23 languages. The survey was conducted towards the beginning of the Covid-19 pandemic and therefore responders' attitudes and beliefs, and their experience of managing SSc, may have changed during the evolving crisis, including through adaptations and changing governmental guidance. Also, specific disease-related information (e.g., disease subtype and severity) was not collected as these factors may have important implications for the impact of the Covid-19 pandemic in patients with SSc. Further research is required to examine the impact on the lived experience of patients with SSc between the first and subsequent 'waves' of the pandemic including once vaccination is available.

In conclusion, the Covid-19 pandemic has resulted in significant impact on patients with SSc routine clinical-care and emotional well-being. Changes to the delivery of different aspects of clinical care have been well-received by patients with SSc, including telemedicine consultations and further research is now required to understand the utility potential,

effectiveness and sustainability of these interventions. The potential for future pandemics also underlines the importance of rising to the challenge of maintaining a continuity of care for patients who require regular clinical follow-up. Patients with SSc require careful individual assessment to determine their risk of disease flare from interruptions in treatment. There are still many practical uncertainties about patient management in Covid-19 and future research is urgently needed to understand the interventions that can ensure continuity of care for a global challenge that may 'never go away'.

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### **Declarations**

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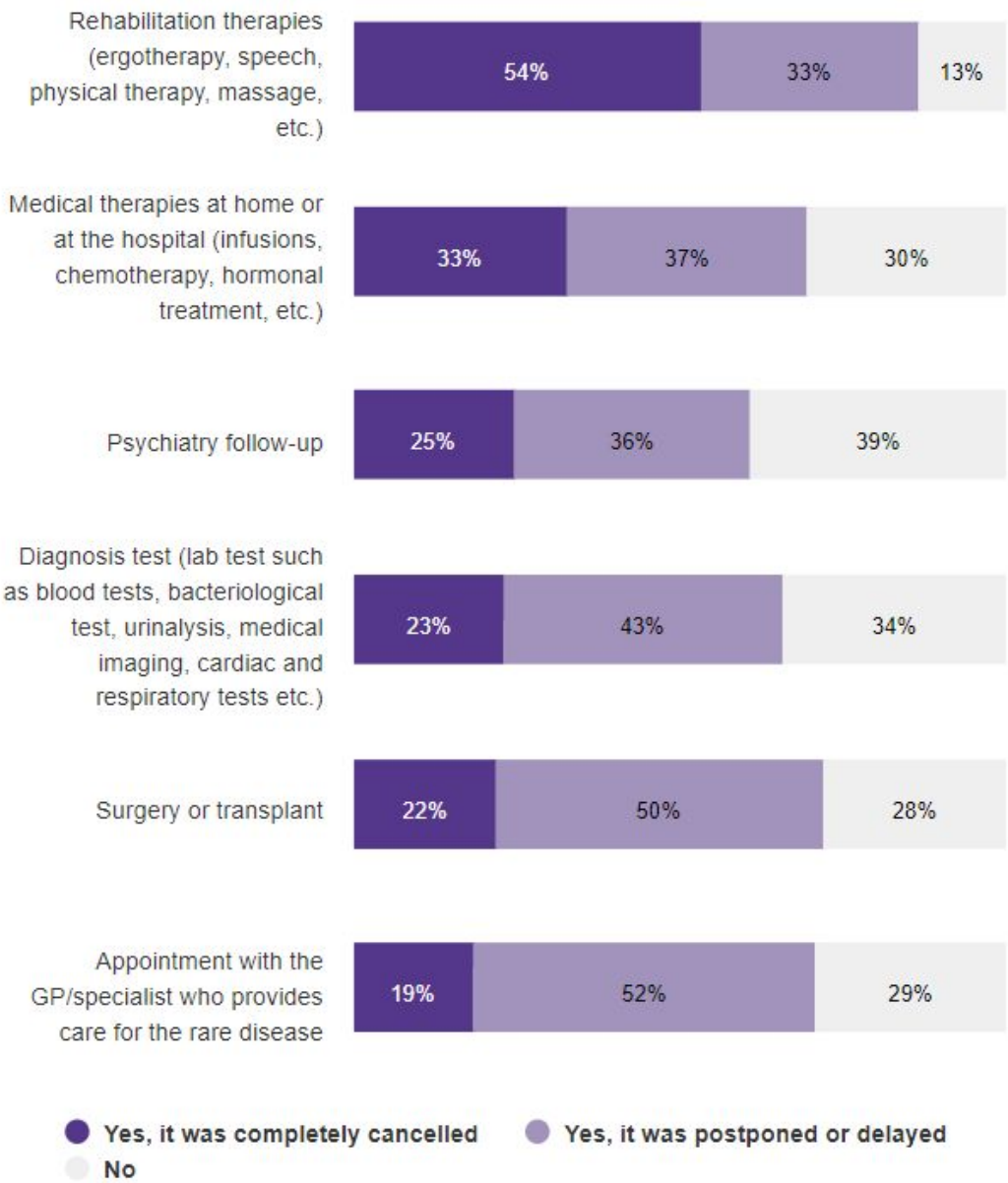


Figure 1: Reported interruption in aspects of usual clinical care provided by healthcare professionals for patients with SSc since the beginning of the Covid-19 pandemic.



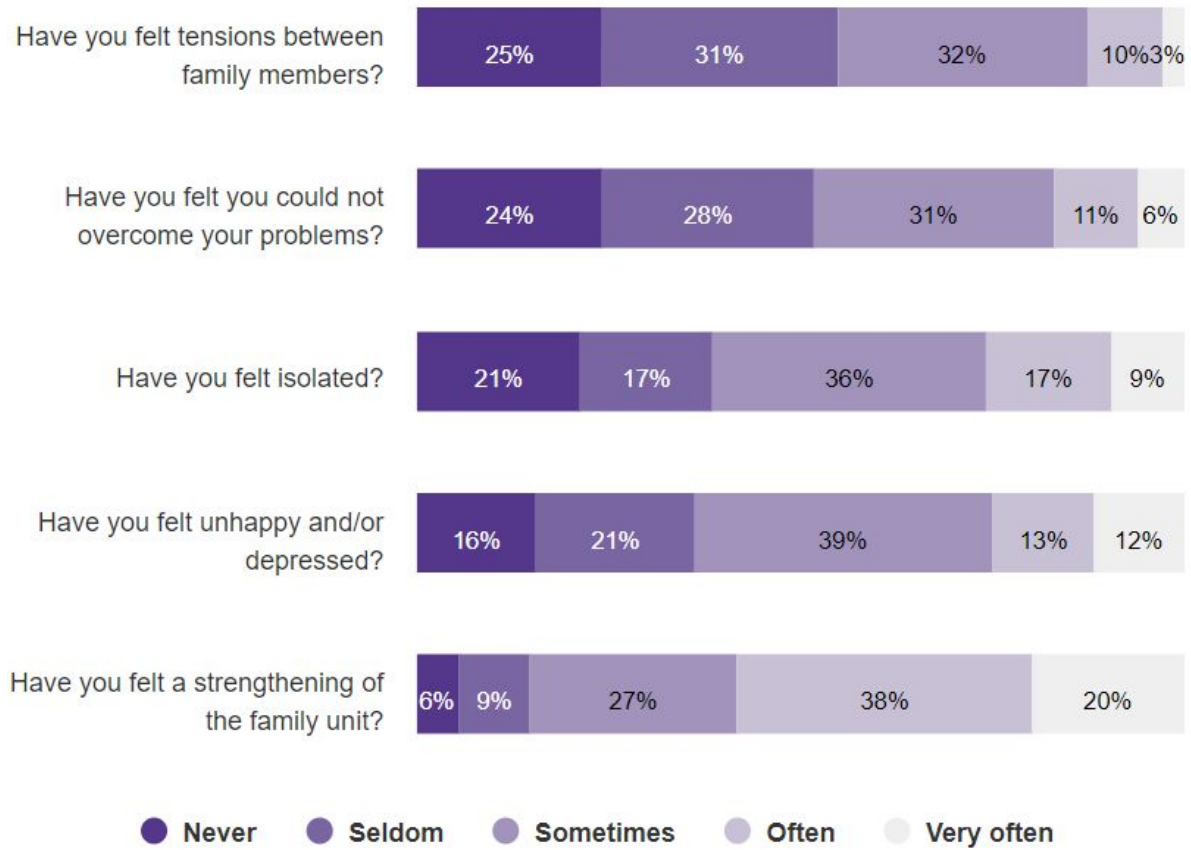


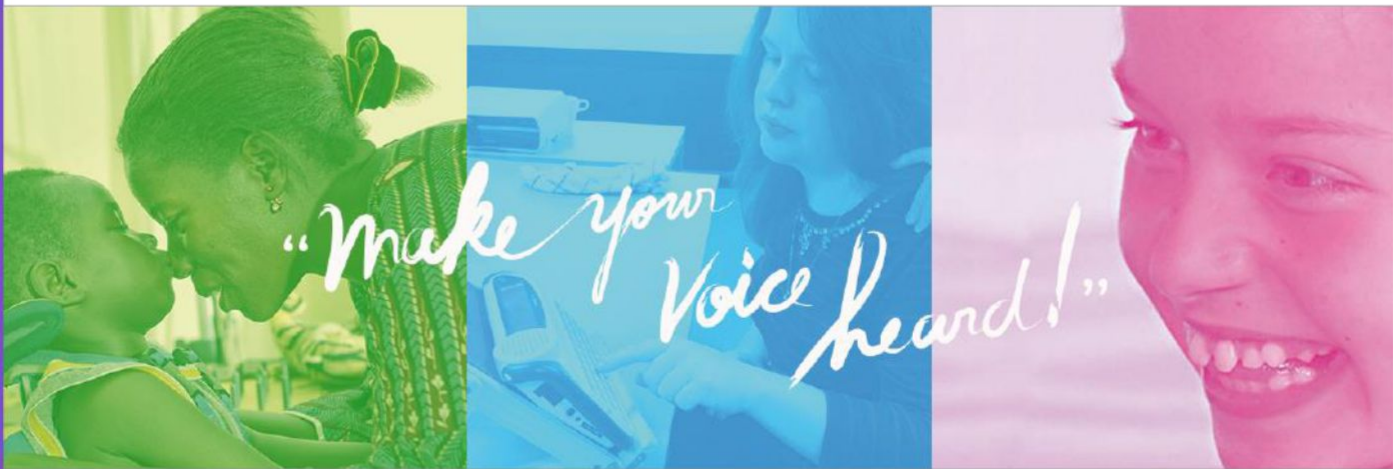
Figure 2: Impact on patients with SSc emotional well-being since the beginning of the Covid-19 pandemic.





# Rare disease patients' experience of COVID-19

April 2020



# COVID-19 SURVEY QUESTIONNAIRE

## Objectives

- Evaluate the impact of COVID-19 on rare disease patients' medical care, social care and well-being.
- Identify measures and facilities that are helping rare disease patients to cope with the pandemic
- Identify aspects that may have a negative impact on rare disease patients care and well-being
- Identify potential long-term consequences of the pandemic

## Goals

- Flag "red signals" during the pandemic to be able to draw messages based on these feedbacks
- Suggest immediate efficient solutions to avoid detrimental consequences on rare disease patients
- Feed our advocacy work with case studies/testimonials
- Prepare our long-term advocacy messages for a potential new wave or another pandemic in the future

## Analysis

Rare Barometer Voices framework will enable to filter and cross the results according to the following criteria:

- Comparison between countries
- Comparison with the general public
- Data by disease/group of diseases
- Patient/carers
- Age
- Gender
- Etc.

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## Translation and reach

Rare disease patients can answer from any country of the world.

The survey is translated in the following languages :

Bulgarian	Greek	Russian
Croatian	Hungarian	Slovak
Czech	Italian	Slovenian
Danish	Latvian	Spanish
Dutch	Lithuanian	Swedish
English	Norwegian	
Finnish	Polish	
French	Portuguese	
German	Romanian	

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## Presentation page of the survey:

Are you affected by a rare disease or are caring for someone affected by a rare disease? Share you experience and tell us how the COVID-19 pandemic is affecting you by completing this survey.

They survey will only take around 15 minutes to answer.

This survey will help EURORDIS-Rare Diseases Europe, a non-profit and non-governmental alliance of 900+ patient organisations to understand your experience of the COVID-19 pandemic.

We will share the overall results of the survey with you and communicate them (without communicating your individual responses) to decision-makers. The goal is to voice the specific needs of rare disease patients' in relation to the COVID-19 pandemic and to propose practical solutions to ensure rare diseases patients are take into account when handling the pandemic.

Your contact details and any written records of your responses during the study will be kept in secure storage which only the research team can access.

If you have any questions while taking part in this survey, you can contact [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org), or call our office on +33 1 56 53 52 63.

## Questionnaire

### 1. How would you like to answer this questionnaire? In your capacity as a ...

- patient
- patient representative
- Parent of a child living with a rare disease
- Grandparent of a person living with a rare disease
- Spouse of a person living with a rare disease
- Uncle/aunt of a person living with a rare disease
- Sibling of a child or adult living with a rare disease
- Other, please specify

} carers category

If you are both a patient and a caregiver (parent, spouse, etc.), please choose in which capacity you want to answer this questionnaire.

### 2. Are the following measures currently in place in your country/region/state in order to fight against the COVID-19 pandemic?

Closure of educational facilities

Social distancing, which includes avoiding mass gatherings, and maintaining distance from others when possible

Lockdown measures

Exceptions regarding containment measures for people living with intellectual disabilities and their caregiver

- Yes
- No
- I don't know

### 3. What level of threat do you think the coronavirus poses to each of the following? (*Comparison with IPSOS survey in 8 countries: <https://www.ipsos.com/ipsos-mori/en-uk/public-opinion-covid-19-coronavirus-pandemic>*)

You personally

[TO CARERS] The person with a rare disease that you care for

Your family

Your country

- Very high threat
- High threat
- Low threat
- Very low threat

### 4. With regard to COVID-19 and in relation to the rare disease you or your family member is affected with, do you feel that you have access to all the information you need?

- Most of the time

- Some of the time
- Seldom
- Never

**5. Are protective equipment such as face masks and plastic gloves...**

For you

[TO CARERS] For the person you care for

For your health professionals

For your social care professionals

- ... available and easily accessible
- ... difficult to find, sometimes not available
- ... impossible to find, not available
- ... not needed
- Not concerned

**6. Since the beginning of the COVID-19 pandemic, have you or the person you care for experienced an interruption in the following aspects of the care provided by healthcare professionals for the rare disease**

....

Rehabilitation therapies (ergotherapy, speech, physical therapy, massage, etc.)

Medical therapies at home or at the hospital (infusions, chemotherapy, hormonal treatment, etc.) Psychiatry follow-up

Surgery or transplant

Appointment with the GP/specialist who provides care for the rare disease

Diagnosis test (lab test such as blood tests, bacteriological test, urinalysis, medical imaging, cardiac and respiratory tests etc.)

- Yes, it was completely cancelled
- Yes, it was postponed or delayed
- No
- Not concerned

[If yes to at least one of the above]

**7. Would you say that interruptions related to the COVID-19 pandemic you are experiencing are...?**

Life threatening

Detrimental to your/her/his health

Detrimental to your her/his well-being

- Definitely
- Probably
- Probably not
- Definitely not
- I don't know

**8. Since the COVID-19 pandemic started, has one of the medicines/ treatments needed for the rare disease been unavailable when you visited your pharmacy or hospital?**

- Yes, temporarily
- Yes, you had to stop taking it or take an alternative
- No

[To those answering no to Q8]

**9. And are you afraid that this might happen in the future if the pandemic continues?**

- Yes, a lot
- Yes, a little
- No

**10. Do you or the person you care for receive/s at least part of the care for the rare disease through a hospital?**

- Yes
- No
- I don't know

[If yes to question 10]

**11. Since the COVID-19 pandemic started, did you experience the following...?**

The hospital/unit that provides care for the rare disease is closed

[TO CARERS] You did not go to the hospital because you are fearful the person you care for might catch COVID-19

[TO PATIENTS] You did not go to the hospital because you are fearful of catching COVID-19

The necessary material needed for the rare disease care was missing because it is now used for patients affected by COVID-19

Being told not to go to the hospital if you or the person you care for affected by a rare disease becomes unwell for other reasons than COVID-19

- Yes
- No

**12. [TO EVERYONE] Have you been tested for COVID-19? (potential comparison with You GOV survey) [TO CARERS] Has the person you care for been tested for COVID-19?**

- Yes, because of obvious exposure to the virus
- Yes, because you/she/he are/is considered at risk
- Yes, because you/she/he had/s first symptoms
- No but you don't consider it necessary
- No but you think you/she/him need/s to be

[To those answering yes to Q12]

**13. Were the results of the test positive or negative?**

- Positive
- Negative
- I am still waiting for the results
- I don't know

[To everyone]

14. Are/were you or the person you care for hospitalised because of COVID-19?

- Yes, in a normal ward for Covid-19 patients
- Yes, in intensive care without intubation
- Yes, in intensive care with intubation
- No

[To those answering yes to Q14]

15. Were your family members allowed to help with the admission and/or care in the hospital?

- Yes
- No but it would have been better if they had been
- No but it was not necessary anyway

[To those answering yes to Q14]

16. Please describe how the rare disease was taken into account in the admission procedure or hospitalisation because of COVID-19...

[open question]

17. Since the beginning of the COVID-19 pandemic and in relation to the rare disease, have you experienced the following ...

Online consultations or any other form of telemedicine online or via  
phone Prescription via email  
Online education and training to help you manage the rare disease yourself

- Yes and this is new to me
- Yes and it was already the case before the COVID-19 pandemic
- Yes and this enables me to keep in touch with my social and/or health professionals
- No

[To those who answered yes to Q17]

18. How would you qualify your experience with ....

Online consultations or any other form of telemedicine online or via  
phone Prescription via email  
Online education and training to help you manage the rare disease yourself

- Very useful
- Fairly useful
- Not very useful
- Not useful at all

If you have any specific experiences in relation to the care received for the rare disease since the pandemic started that you would like to share with us, please relate this experience in the sections below.

19. Please report here positive experiences you had in relation to the care received for the rare disease since the pandemic started. Please provide as much detail as possible.

[open box]

20. Please report here negative experiences you had in relation to the care received for the rare disease since the pandemic started. Please provide as much detail as possible.

[open box]

21. Do you need the following support and do you still have access to them since the COVID-19 pandemic started?

Social worker support

Psychological support

Support for house chores and daily tasks

Home care (nurse, personal assistant for self-care etc.) Day care (access to a day centre, occupational activities)

Institutional long-term care (living in a care facility)

Respite care or resource

center Adapted school

Family, friends or neighbours support

- Yes I need this support and I can still access to it
- Yes I need this support but I receive less support since the pandemic started
- Yes I need this support but it stopped completely since the pandemic started
- I need this support but have not received it before or during the pandemic
- No I don't need this support

[TO THOSE ANSWERING YES TO SPECIFIC ITEMS IN Q21]

22. For what reason has the following support decreased or stopped completely?

Social worker support

Psychological support

Support for house chores and daily tasks

Home care (nurse, personal assistant for self-care etc.)

- Because of lack of personal protective equipment such as gloves and masks available for the person providing the support
- Because of lack of personal protective equipment for yourself and your family - Because the person is ill and no one can replace her/him
- Other
- I don't know

23. What is your current occupation? (Eurostat)



- Employed
- Unemployed and able to work
- Unemployed and not able to work (long-term illness, disability)
- Leave of absence
- Retired
- Student
- Homemaker
- Self employed
- Other, specify

[TO EMPLOYED]

24. In order to adapt to the COVID-19 pandemic, does your employer allow the following... :

- More flexible working hours
  - Reduction of number of working hours
  - Possibility to work from home
- Paid carer leave

- Yes and this was already imposed by public authorities
- Yes and this was advised by public authorities
- Yes and this an initiative from my employers
- No

[TO EMPLOYED/SELF EMPLOYED]

25. Please choose the sentence that best describes your situation, since the COVID-19 pandemic started.

- I work from home
- I had to significantly reduce my number of working hours -
- I had to stop working
- I continue to working normally -
- Other, please specify

26. Since the COVID-19 pandemic started, how often... (Comparison ISSP study, 2011, translated, Juggling care 2017)

- Have you felt unhappy and/or depressed?
  - Have you felt you could not overcome your problems?
  - Have you felt isolated?
  - Have you felt tensions between family members?
  - Have you felt a strengthening of the family unit?

- Never
- Seldom
- Sometimes
- Often
- Very often
- Can't choose

27. Including yourself, how many people – including children – live regularly as members of your household?

- 1
- 2
- 3
- 4
- 5
- 6 or more

**28. How many children are currently living in your household?**

- 0 -
- 1 - 2
- 3 -
- 4 - 5
- 6 or more

**29. Including yourself, how many people live with a rare disease in your household?**

- 1 -
- 2 - 3
- 4 -
- 5

**30. How old are you ?**

- Under 15
- 15-17
- 18-24
- 25-34
- 35-49
- 50-64
- 65 or older

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